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Public attitudes towards opt-out testing for HIV in primary care:

a qualitative study

Abstract

Background
The rate of new HIV infections in the UK continues to rise, with one-quarter of cases undiagnosed. Opt-out HIV testing — in which tests are routinely offered to all patients, with the offer to decline — have proved effective in antenatal care. Pilot studies of HIV opt-out testing at GP registration and acute medical admission to hospital have described service-level issues and the clinician's perspective, but not the views of the general public.

Aim
To further understand the public's perspective on opt-out testing for HIV in England.

Design and setting
Focus groups (n = 9) with a total of 54 participants in Brighton, England, where HIV prevalence is high.

Method
Quota sampling on sexual orientation, age, sex, and testing experience was applied to groups with high and low HIV prevalences, and analysed using framework analysis.

Results
Opt-out testing for HIV was acceptable. Testing on GP registration was regarded as a more appropriate setting than acute medical admission. Participants from groups in which HIV has a higher prevalence felt HIV testing required consideration that may not be possible during acute hospital admission. However, there was concern that screening would still be targeted at groups in which HIV prevalence is higher, based on clinicians' judgement of patients' behaviours, sexuality, or ethnicity.

Conclusion
The opt-out method of testing for HIV must be routinely offered to all who are eligible, to increase test uptake and to prevent communities feeling targeted. Any pressure to test is likely to be poorly received. Inaccurate concerns about medical records being shared with financial services are a disincentive to test. Primary care should be an active setting for opt-out HIV testing.

Keywords
general practice; HIV; policy; qualitative research.

INTRODUCTION

Approximately 24% of UK residents with HIV are unaware of their infection.[1] Late diagnosis is associated with negative health outcomes, increased potential for transmission, and increased financial care costs. Primary care has a fundamental role in the prompt detection of illness but early opportunities to treat are being missed.

Opt-out testing for HIV — in which patients are individually informed that everyone is routinely tested, unless they decline (opt out) — has achieved 96% acceptance in antenatal settings; it has resulted in the number of women undiagnosed post-delivery being reduced by more than half and mother-to-child transmission falling from 8% to 2%.[2] This success encouraged the Department of Health to commission opt-out testing pilots in areas of England where estimated prevalence is >2/1000 among 15–59 year olds.

The offer of an HIV opt-out test is proposed for all adults when they register with a GP or on acute medical admission to hospital. This is supported by the British HIV Association, the British Association of Sexual Health and HIV, the British Infection Society (now the British Infection Association),[3] and guidelines from the National Institute for Health and Care Excellence (NICE) guidelines.[4,5] The 3Cs & HIV Programme[6] from Public Health England promotes general practice involvement in sexual health, including opt-out HIV testing, using dedicated trainers, support, and monitoring.

The Health Protection Agency (HPA) conducted eight pilots in community, primary, and secondary care during 2009–2010 to investigate the feasibility of the proposals. Pilots in primary care used point-of-care tests at new-patient registration. All pilots were considered successful, detecting new HIV infections at greater than the 1 in 1000 threshold for cost effectiveness.[2] However, these aggregate measures of the acceptability of the opt-out offer did not investigate differences in attitude between patients from communities with high HIV prevalence rates (men who have sex with men [MSM] and black African men and women) and those with low prevalence rates (heterosexual). A more detailed understanding of nuances between these groups is required.

This qualitative study used focus groups to consult members of the public in one of the high-prevalence areas included in the original pilot studies (Brighton, HIV prevalence 7.59 per 1000).[1] It aimed to elicit attitudes and concerns around the acceptability of HIV opt-out testing and to identify any differences between participants from demographic groups with high and low prevalence of HIV.

METHOD

Design

The supportive setting of focus groups:

- promotes open, honest interaction between participants;

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How this fits in

In pilot studies commissioned by the Department of Health, the acceptability of HIV opt-out testing at registration with a new GP or at acute medical admission to hospital was inferred from the percentage uptake of the test and questionnaire responses. This research is the first to investigate the acceptability of opt-out testing qualitatively. It identifies a difference in the degree of acceptability between different demographic groups: those with higher HIV prevalence (men who have sex with men, black African men and women) and those with lower prevalence (heterosexuals). This could be minimised by ensuring that the offer to test is universally applied. It also found that opt-out testing was more acceptable when offered at new-patient registration with a GP than on acute medical admission to hospital. This suggests a public desire for HIV testing in primary care.

- aids detailed exploration of issues and attitudes;[7,8] and
- highlights insights, beliefs, and experiences of individuals.[7]

Participants

Nine distinct groups of people with a variety of HIV-testing experiences were recruited using a quota sampling framework based on sexual orientation, age, sex, and ethnicity. Black African men and women were targeted for recruitment to the study as the prevalence of HIV is 30 times greater among members of this group than that of the general population.[1] However, it proved difficult to recruit black African women who were HIV negative in this disproportionately white part of England. A group of interested black African women with HIV were accessed via an HIV community support group. All other groups were HIV negative and/or untested. In total, 54 participants were recruited; these were aged ≥17 years old (average age of 28.9 years, range 17–58 years) (Table 1). Each focus group consisted of an average of six people (range 4–9 people, Table 2) and lasted 45–120 minutes.

Procedure

Participants were recruited through email or letters to community organisations, and via a classified advertising website. Individuals who were interested were invited to contact the team directly, and were recruited to the appropriate focus group on a first-come-first-served basis. Groups were held in local community venues (a lesbian, gay, bisexual, transgender [LGBT] youth project; young people's centre; Terrence Higgins Trust; Friends' Meeting House; The Sussex Beacon HIV care centre; and the Black and Minority Ethnic Community Partnership Centre) between June and August 2011. Consent was obtained for field notes, audiorecording, and anonymous transcription of the group sessions. Participants received £15 recompense.

Focus groups

Discussions were facilitated by an experienced qualitative researcher and an assistant. A topic guide was developed (Box 1) from a literature search, issues raised in a previous study,[9] and clinician input, employing open questions to elicit dialogue and unmediated opinions. Discussion was guided towards:

- aspects of HIV testing;
- exploring participants' experiences, thoughts and potential barriers and/or motivators to testing;
- subsequent hypothetical situations, in which a test might be offered; and
- the opt-out testing proposals, which were explained as an introduction to the final section of the interviews.

Data analysis

Transcription was undertaken externally and transcripts were independently analysed twice, using framework analysis;[10] this assists accurate reporting of participants' experiences, opinions, and meanings,[11] and provides a detailed and complex summary of the data. Recurrent themes were identified to enable organisation, description, and interpretation. Data immersion was achieved through a repetitive process of coding themes and sub-themes from the recordings and transcripts, followed by narrative interpretation.

Triangulation

Analysis was triangulated by repeated discussion of thematic classification and interpretation between two researchers, and a third researcher who resolved minor differences over the ranking of sub-themes through discussion and consensus.

RESULTS

Opt-out testing is acceptable

All groups regarded opt-out HIV testing affirmatively; individual and public benefits

Table 1. Participant characteristics (*n* = 54)

Demographic	Participants
Age, years	
Range	17–58
Average	28.9
Sexuality	
Heterosexual	38
Homosexual/bisexual	14
Not reported	2
Sex	
Male	34
Female	20
Ethnicity	
White British	28
White other	4
Black African	14
Hispanic	1
Mixed	2
Other	2
Not reported	3
HIV status	
Negative/untested	49
Positive	5
HIV testing history	
Tested	35
Never tested	19
Last test location	
General practice	3
Genitourinary medicine/hospital	17
Community service	3
Not reported	31
Employment status	
Employed/self-employed	17
Unemployed	15
Full-time education	8
Not reported	14
Highest educational qualification	
≤GCSE	15
A˙ levels/diploma	13
≥Degree	18
Not reported	8

to diagnosis and treatment were identified:

'I personally think this opt-out, 15–59 opt-out testing at your GP is a great idea to trial. [...] *I think you're going to get more people tested that way, definitely.'* (Participant 2, older MSM, tested HIV negative)

Offering the test to those aged 15–59 years was acceptable, although restricting it at 59 years was felt to be too low. The main barriers to testing were expectation of a negative result (therefore, the test might be considered unnecessary), and the potential for a positive result (especially among higher prevalence groups). The documentation of testing within medical records and its potential impact on future financial applications was also a concern:

'The only problem with getting it done at the doctors is it's not anonymous so if you then want to get health insurance in later years you have to admit having the test which will make your premiums go up possibly.' (Participant 3, older heterosexual man, tested HIV negative)

Appropriate circumstances of opt-out offer: location and timing

Testing at GP registration was considered appropriate and acceptable overall, however, younger participants in particular raised confidentiality concerns around testing in a family GP:

'I would be worrying if my mum or dad found out because they have the same GP as me, so I'd be like, "What if they find out? What are they going to think of me?"' (Participant 1, younger heterosexual woman, negative/untested)

Acute hospital admission was felt a less appropriate setting for an HIV test. Higher prevalence groups (MSM and black African) were most concerned about this, reflecting their awareness of a test's greater potential for a life-changing outcome, and their desire for time to consider testing:

'I don't think it would be wise for you to offer HIV tests to someone who comes into the hospital for another thing [...]. *He himself should be prepared psychologically.'* (Participant 1, black African man, negative/untested)

'If it was relevant to treatment I suppose I would feel okay about it [...] *but if it was just random I would feel it was quite an invasion of my ...* [privacy].' (Participant 5, older MSM, tested negative)

'Having that little bit of breathing space might just be enough for them to make an informed decision.' (Participant 1, younger MSM, tested HIV negative)

Clinicians' pressure to test

Several participants (particularly in higher prevalence groups) expressed concern that doctors' status and authority could pressurise people to test against their will:

'Doctors, sometimes they have an overwhelming influence for patients so, when somebody of that calibre says go for a test, it's very hard for you to say no to someone who is just trying to help, from his own perspective.' (Participant 1, black African man, negative/untested)

Any perceived pressure to test was considered a factor that would discourage acceptance of the test.

Social pressure to test

Several members of groups in which the prevalence of HIV is somewhat low articulated a social pressure for those who had been at risk to test, and considered declining a test selfish:

'... what if somebody says "Well I don't care, I just don't care about it"? I think that's wrong, that's morally wrong in my eyes.' (Participant 5, older heterosexual woman, negative/untested)

Inferred judgement from clinicians

Groups in which HIV prevalence is high, and some younger groups, inferred feeling specifically targeted due to their sexuality

Table 2. Focus-group composition

Focus group	Composition	Group members, *n*	Mean age, years (range)
1	Younger heterosexual men, negative/untested (≤24 years)	5	22 (19–24)
2	Older heterosexual men, negative/untested (≥25 years)	6	31 (25–43)
3	Younger heterosexual women, negative/untested (≤24 years)	6	21 (18–24)
4	Older heterosexual women, negative/untested (≥25 years)	9	44 (27–58)
5	Younger MSM, tested HIV negative (≤24 years)	5	21 (19–24)
6	Older MSM, tested HIV negative (≥25 years)	5	37 (31–51)
7	Younger MSM, untested (≤24 years)	4	17 (17)
8	Black African men, negative/untested	9	30 (23–41)
9	Black African women, tested HIV positive	5	37 (32–47)
	Total	**54**	**28.9 (17–58)**

MSM = men who have sex with men.

Box 1. Topic guide

Broad exploration of experience and attitudes

1. *'So everyone here has* (*has not*, as appropriate) *had a test for HIV at one time or another — I wonder what people made of those tests and how they felt about the whole experience?'*
   Probes: What was important/unimportant about it for you? Why that place? How was the process? How do you feel it went? Requested a test, or offered a test? Is there anything that would have made it easier or better? Any good/bad experiences? Do people know where (else) they could go? Access. Staff. Emotional experience. Confidentiality.
2. *'What might help make you take tests again — if anything?'*
   Probes: Are there any circumstances that would be more or less likely to encourage testing? What could be done to improve testing — for yourself or others? Consent. Ability to decline. Relationships. Pregnancy.
3. *'What might stop people from testing for HIV — if anything? Do you think optional testing is effective? Is optional testing for HIV (specifically) likely to be effective?'*
   Probes: Are there public and/or individual benefits to testing? Is it OK for people to decline a test when it's offered? Moral codes. Who will and won't accept. Ability to decline tests.
4. *'Is HIV testing different from testing for other sexually transmitted illnesses?'*
   Probes: Is there anything about the test, or the experience that might make HIV testing different?
5. *'Do you think there are any aspects of HIV testing that are specific to your community?'*
   Probes: Immigration/residency concerns. Cultural difference. Implications for family overseas. Relationships. Work permits. What could we do differently?
6. *'How do you get information about health care services (and HIV services in particular)?'*
   Probes: Levels of awareness/knowledge about HIV. Levels of awareness/knowledge about health services. Comfort in access.

Hypotheticals

7. *'How would it be if you were admitted to hospital — for any reason (for example, having your tonsils out, or a suspected heart attack admission) — and you were offered an HIV test? Would you say yes/no? Why?'*
   Probes: Would you feel comfortable? Would you mind/be pleased? Levels of illness/consent. What might your feelings/concerns be? How would you like to get your results? Consent. Confidentiality. Nurse/doctor location. If you would not be comfortable, under what conditions would it be acceptable?
8. *'How about if you were registering with a new GP for the first time and you were offered an HIV test (at your new-patient check)? Would you say yes/no? Why? Do you imagine it would be the nurse or the doctor offering the test?'*
   Probes: Would you feel comfortable? Would you mind/be pleased? What might your concerns be? How would you like to get your results? Care pathway, groups/services to contact following diagnosis. Would testing at your GP surgery or the hospital be more preferable?

Explain opt-out testing

'There is a proposal to introduce "opt-out" HIV testing in the NHS in areas of high HIV prevalence, such as Brighton and Hove. If introduced, this will mean that any of us — man or woman, aged 15–59 years — will be offered an HIV test whenever we register for the first time at a GP surgery (family doctor), and when being admitted to hospital. When an HIV test is offered in this way, you can accept or decline the test, and you will have to give your verbal permission for the test. (If you are unable to consent [for example, you are unconscious, drunk, in great pain, or in distress] ethical NHS practice says you should not be offered the test).'

Views of opt-out HIV testing

9. *'How do you feel about the introduction of this new "opt-out" HIV testing policy? Do you think people will accept/decline? Why might they?'*
   Probes: Can you see any advantages/disadvantages to this? Why do you think an approach like this might be introduced (high risk versus low risk)? Do you think it will be effective? How do you think other people might feel and react if they were offered an opt-out test? Do you think being offered an opt-out test could change anything? How would you have felt being offered an HIV test at 15? Is it OK for people to decline a test when it's offered? Does it matter if that's with a GP or in a hospital? Consent. Normalising/Stigmatising. Appropriate targeting. Appropriate age.
10. *'Do you think people would feel able to decline a test when it was offered — if they wanted to decline?'*
    Probes: Why do you think people might decline a test? Would the offer of an opt-out test be appropriate for everyone? How do you think it should it be offered? Should people test?
11. *'How do you think the surgery/hospital staff will react to people who decline a test? Is it OK for people to decline a test when it's offered?'*
    Probes: Does it make a difference if that's in a GP or a hospital?
12. *'How would you prefer HIV testing to be provided?'*
    Probes: Is there a right and a wrong way to do it? Where would you like it? (GP surgery/hospital/elsewhere) Opt-out, or only if asked? Who by? Doctor/nurse? Age. Sex etc.
13. *'How do you think people who get a positive result (that is, are told they have HIV) might feel about this type of opt-out testing after they're diagnosed?'*
    Probes: Who might benefit from a new policy like this? What do you think might be the implications of having HIV (stigma/relationships etc)? What care do you think should be available?

or race, or that they were being judged for their sexual practices:

'It's a fear of judgement as well [...], *a couple of times I've been asked — it just seems like I'm not even talking about that so why do you even bring it up? Are you trying to suggest that I've got something? And, actually, when you talk to them it's just something that they do as standard procedure. That's fine, but you obviously think you're being judged.'* (Participant 2, younger MSM, tested HIV negative)

'... what you would see happening at some surgeries would be that the black*s or Asians would be asked to do the test more than their white counterparts, because it's assumed that people from Africa are more likely to have HIV. So, if we have that system, it goes back to profiling.'* (Participant 6, black African man, negative/untested)

Normalisation and the universal offer

HPA guidance recommends the routine offer and recommendation of opt-out HIV tests to all eligible patients, and participants in this study embraced this as a positive step towards the normalisation of HIV testing:

'As long as HIV testing remains in the realms of GUM [genito-urinary medicine] *clinics then it's never going to break away from the stigma of a badly behaved sexual deviant, and I think we need to normalise it. I think if it's thrown in the catchment of general health screening then it just blurs that specific area.'* (Participant 2, older heterosexual woman, negative/untested)

Crucially, an explanation of the universal offer and the opportunity to opt out were felt to increase the likelihood of acceptance.

The importance of implementing the strategy for all eligible persons to prevent high prevalence groups feeling targeted was emphasised:

'That's why it's important to make it like a normal thing so they don't feel like they've been picked out.' (Participant 4, younger heterosexual woman, negative/untested)

DISCUSSION

Summary

Opt-out testing for HIV was broadly acceptable to this sample. Nearly all participants felt that registering with a GP practice was a suitable opportunity for opt-out testing and more acceptable than testing on hospital admission. The offer of an HIV test may be received as a judgement of an individual's sexuality, ethnicity, or behaviour, unless it is clearly explained and understood that the test is offered to all patients. Some participants in groups in which HIV prevalence rates are high, however, voiced reservations about agreeing to a potentially life-changing decision without time for forethought.

Strengths and limitations

This is the first qualitative study to explore public opinions around this proposal put forward by the Department of Health. This study's sample resided in an area of high HIV prevalence (Brighton, England), had a broad range of HIV testing experiences, and were grouped according to high and low HIV prevalence communities to put participants at ease and encourage the expression of ideas. This enabled the identification of differences and a greater depth of analysis of attitudes towards opt-out testing than was possible within the HPA pilot studies'.[2]

A limitation of the study was the failure to recruit MSM ≥25 years old who had never tested for HIV. HIV prevalence continues to increase in MSM.[1,12] MSM ≥25 years of age who have not been tested have been identified as a hard-to-reach group,[13] inhibited from accepting HIV tests by fear of a positive result.[14] This group is a key target of HIV opt-out testing and the policy's success depends on it being accepted by communities in which HIV prevalence rates are high.[15] Recruitment failure meant that it was not possible to obtain the views of certain groups that would have been beneficial to obtain including black African women who were HIV negative or had never tested.

Participants who felt passionately about HIV testing may have self-selected themselves to attend. However, the level of HIV awareness varied both between and within groups and was not felt to be a major cause of participation bias within the current findings. The influence of the researchers on the focus groups' discussions was minimised by using a pre-written topic guide; one researcher's role as a general practice registrar was not revealed until the group ended.

This study explored the implications of the national HIV opt-out testing policy. The results of this study are generalisable to areas where the HIV prevalence is >2/1000, and will be affected by this policy.

Comparison with existing literature

Studies in the UK and the US have consistently found acceptance and approval of HIV opt-out testing among patients, but have also found significant unwillingness on the part of clinicians to offer tests.[2,16] In one HPA pilot in secondary care, 91% of patients offered a test accepted it, but only 40% of eligible patients were offered the test; and in another pilot study the test rate was between 3% and 22%.[17]

The acceptability of the opt-out testing policy in the HPA pilots was based on rates of test uptake and questionnaire responses. However, in one hospital-based study, the offer rate to eligible persons was only 6–22%.[18] In another hospital study, failure to offer a test to all patients resulted in 67% of those with HIV remaining undiagnosed.[17] It appears that the test offer was frequently targeted and not routinely applied. Australian studies have also shown variable rates of test offer between individual clinicians.[19]

These findings have identified that targeting tests to selected patients has a negative impact on patients' acceptance

of tests. The comfort of staff with offering tests and managing reactive results was assessed in a third pilot, with 63% (range 57–75%) of staff anticipating discomfort prior to the testing phase; following the pilot, however, staff reported high levels of satisfaction and no negative impacts on the department.[20] Training interventions in GP surgeries in the UK have been shown to significantly increase staff comfort with offering tests and testing rates in the absence of financial incentives.[21] The 3Cs & HIV Programme[6] launched in January 2013 by Public Health England promotes greater involvement of general practice in sexual health (including opt-out HIV testing) through dedicated trainers, support, and monitoring.

A separate study of hospital healthcare staff attitudes towards opt-out testing identified primary care as the 'best' setting due to its association with screening.[22] These sentiments were also expressed among this study's participants.

A previous study into public attitudes to opt-out HIV testing identified that participants from groups in which HIV prevalence is low, although generally positive about its introduction, were keen to maintain their right to opt-out while simultaneously asserting that individuals from groups with a higher HIV prevalence rate had a moral obligation to test.[9] This study confirms this; finding lower-prevalence groups considered declining a test to be irresponsible if they judged people to be at greater risk.

One pilot study[23] identified a legacy of misinformation among medical professionals regarding the impact of HIV testing on mortgage and insurance applications. There is evidence that medical professionals are misinforming patients[24] and incorrect beliefs were identified in this study. Such erroneous concerns may present a barrier to testing.[25] A negative result to an HIV test does not need to be declared on applications for insurance.[26] It should also be noted that, although opt-out testing requires verbal consent, a pre-test discussion is no longer required unless a patient asks for it or is felt to need it.[27]

Implications for practice

Clinicians should be mindful of the low level of public awareness of the opt-out testing proposals. Most groups discussed how the offer of an HIV test could be interpreted as a judgement of their behaviour, sexuality, or ethnicity if the universal nature of the offer was not explained and understood; this could potentially discourage testing and increase stigmatisation. This was a particular concern among MSM and black African participants. Prior explanation of the routine, non-discriminatory nature of opt-out screening for HIV was reassuring, and should form part of every offer. A poster campaign[28] has been developed for settings where the policy is implemented. A confidentiality reminder may also encourage people to test; exerting any pressure, however, is likely to adversely impact on the therapeutic relationship.

The HPA pilot studies were deemed cost effective according to estimates inferred from US studies[29,30] that analysed a model for testing every 3–5 years, and a French study[31] that reviewed one-off screening. The initial start-up cost (including time constraints and the purchase of point-of-care testing) may inhibit GPs from engaging with the proposals. The pilot studies in primary care included incentives of £375 (average) for participating, plus £10 per test conducted, and used point-of-care tests costing an average of £7.60 each. In one UK paper, financial reimbursement has been found to be key to increasing primary care involvement in HIV care;[32] however, training interventions in GP surgeries have also been shown to increase testing rates in the absence of financial incentives.[21]

This study identified that the policy will undergo a 'settling-in period' within the public understanding, but adjustment will also be required in the medical profession. A study in a UK teaching hospital found the stigmatisation of HIV was a significant barrier to consultants offering HIV tests.[33] Proper implementation of routine, non-targeted, opt-out testing represents a significant change in HIV testing that may contribute to its normalisation and acceptance among the public and the profession. It is, however, acknowledged that very little opt-out testing for HIV has so far been implemented outside of centres involved in the HPA pilots;[1] particularly in primary care.

These findings suggest a public desire that primary care be a driving force for the promotion and delivery of HIV testing.

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Ethical approval

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Provenance

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Competing interests

The authors have declared no competing interests.

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